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Article type : Comment

Men don't talk about their health, but will they CHAT?

The potential of online holistic needs assessment in prostate cancer.

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Men don't talk about their health is a familiar trope. Evidence suggests that in the United States (US) and in the United Kingdom (UK) this is indeed the case. A survey of five hundred men in the US over the age of eighteen reported only 7% discussing their health with their peers [1]. Only 42% of men surveyed were prepared to consult a health care professional over a worrying symptom [1]. A UK based study has shown a marked gender disparity in General Practice consultation rates in all age groups up to the age of 75 [2]. Support group membership appears similarly gendered. Women in the USA and in the UK have been found to outnumber men in cancer support groups by 3 to 1 [3]. Urological problems carry a particular stigma as a well-known UK television GP has commented, 'Men feel embarrassed to talk about their health and if it's anything below the waist, forget it' [4].

At diagnosis and in follow-up or monitoring of prostate cancer, men may be reluctant to express their concerns for a variety of reasons including reticence and a wish to avoid 'wasting the doctor's time'. However, the persistence of physical problems regardless of treatment regime and the associated long-term psychosexual and psychological consequences are evident. While the importance of outcomes in addition to those of survival and recurrence is accepted, research documenting the scale of unmet needs and elucidating their impact on quality of life continues to proliferate [5]. Though men may be less proactive in help-seeking than women, in the UK pressures

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on resources, limited consultation time and changing prostate cancer care pathways may limit the opportunity for face to face discussion of concerns.

In an earlier Comment we described the potential of an online assessment for the identification of prostate cancer patients' information needs and other concerns to their health care teams [6]. The last 5 years have seen a rapid escalation and expansion of access to digital technology in the general United Kingdom population. Men with prostate cancer are known to access the internet for information and advice in the United Kingdom usage is increasing among patients from lower socioeconomic groups in the [7,8]. Online support groups are gaining popularity suggesting that men may find the comparative anonymity of online communication more acceptable.

We previously described a potential extension of our needs assessment system to include a wider range of concerns, and suggested that such a system might find a place within the new models of care and follow up recently introduced in the UK in response to demands on resources and NICE guidelines [9]. A three-year collaboration involving patients, clinicians, academics and an IT provider has since enabled us to develop a prostate specific online holistic needs assessment system (CHAT-P). While Holistic Needs Assessment (HNA) has been identified by the National Cancer Survivorship Initiative as an integral element in cancer follow up care, paper-based HNAs have had limited uptake and evidence of positive impact is lacking. Digital systems have been piloted; however, their content is generic.

CHAT-P (Composite Holistic Assessment Tool-Prostate) is the first prostate-specific HNA developed for an online platform. Additionally the system provides links to reliable sources of advice and support in response to the selection of certain items, in order to facilitate self-management. Links are primarily to the Prostate Cancer UK website which provides information on all aspects of prostate cancer in a variety of formats as well as telephone access to a specialist nurse. A digital design offers a number of advantages over paper; it allows the HNA to be adaptive, enabling men to choose items from a broad menu of domains that are relevant to them and to disregard those that are not. As such, CHAT-P encompasses a wide range of concerns that may arise as a result of prostate cancer at different stages along the care pathway or as a consequence of particular treatment modalities. Its output includes a summary of needs identified and a partially-completed care plan to be finalised and agreed by the patient and a member of his specialist team or a primary care health practitioner depending on the particular patient pathway. Table 1 summarises these benefits.

CHAT-P has been developed as an iterative process with users playing an active role in all aspects from item selection to question format and design. Qualitative investigation of men's response to the system has taken place with 22 men post curative surgery, men with metastatic disease and men on active surveillance recruited from urology clinics in the West and North Midlands and South Yorkshire. The age range of the men was 65-79 years with a median of 72 years. Responses have been positive and even men with limited or no experience of digital technology have been enthusiastic. A number of advantages were identified,

B010: 'I would like this just to be able to quickly get the information that I want. At the moment I sit on the computer and wade through the internet and pick out bits and pieces, but it just brings it all into one place'.

D004: Well obviously doctors have only got a certain length of time and you can only ask them so much. And obviously, you know, you come away and think, oh I wished I'd asked him that. So something, a tool like that is handy because you could go into it and find out more, the things you've forgot to ask them, and obviously the things you haven't got time to ask. So yes it would be a useful tool.

B009: I think more than anything it's just reassurance that some of the things that you've experienced are normal, whereas you worry that they're not normal when you're experiencing them.

CHAT-P is now being trialled as the basis of an intervention in a primary care based feasibility study [8]. The study will report in 2018. Early indications are that men are using the system to identify a range of concerns with psychological and psychosocial issues particularly prominent.

Mental health too is a topic that men are reluctant to discuss. Men with prostate cancer suffer an increased risk for mental health problems over men in the general population and the identification, treatment and management of anxiety and depression has been recommended as a key clinical outcome [10]. CHAT-P may enable men to overcome the barriers to disclosure of emotional and psychological issues as well as helping them identify and articulate their problems.

Men may be enthusiastic in their response to an online system, and using digital technology in assessment offers a means of reducing patient burden. However, identification of needs is only a first step. There must also be a willingness to adopt and adapt to new technology among health care providers. Implementation science can provide useful insights as to how this may be achieved. In addition to recognition by hard-pressed clinical teams of the importance of addressing men's holistic concerns, confidence that this is achievable is required. To this end good communication within and beyond settings, knowledge of resources and points of referral are critical.

If CHAT-P encourages men to talk, it is equally important to ensure that those best placed to help will listen and respond.

Ethical Approval

Ethical approval for the study was granted by Yorkshire and Humberside Research Ethics Committee on 15th February 2014 Reference 15/YH/0021

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Conflicts of Interest

None declared

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Table 1: Benefits of a prostate specific online Holistic Needs Assessment system

- The HNA is accessed through a secure login system and can be completed at home
- Responses are saved automatically allowing completion in stages if preferred
- Men chose relevant topics from a range of domains listed on an initial screen
- Branching structure allows identification of specific concerns within broad domains
- Mandatory questions within physical and psychological sections allow identification of 'red flag symptoms.' Positive response triggers an alert to contact a health professional
- System contains links to reliable sources of information, advice and support to facilitate patient self-management
- Generates a summary document and semi auto-completed care plan to be completed with a health care professional
- The output can be shared electronically or through printable PDF between the patient, his specialist team and primary care